Transition – intellectual disability

Information on transition for parents/carers of a young person with an intellectual or developmental disability

Transition is a process of planning, preparing and moving from a paediatric to an adult health care service. It usually happens during a time of many other changes for your young person, like leaving school, legally becoming an adult, and changing social benefit categories. Preparing for transition involves preparing you and your young person with the knowledge to navigate this process. All decisions should be centered on your young person, what is in their best interest and their right to live a full life, e.g. with good health care and participation in society, while also respecting your role as carer.

Transition ideally is a gradual process and starting early will give you the time to prepare. Discussing transition with your healthcare teams can start when your young person is around the age of 14. This information sheet provides guidance through some of the common practical issues. Many of the services mentioned are based in New South Wales, however most information is relevant to all of Australia.

Finding support
As a parent/carer of a young person with an intellectual or developmental disability, knowing where you can find support can be useful. You are not alone and it is healthy to turn to others for additional support.

People or organisations that may be helpful:
• Family and friends
• Your general practitioner (GP) or your young person’s medical, nursing and healthcare team members
• Support workers or social workers
• Psychologists or counsellors – ask your GP or child’s health or medical team for a referral
• Carer support and advocacy
  - Carers NSW
    Call: 1800 242 636
    Visit: carersnsw.org.au
  - Carer Gateway
    Call: 1800 422 737
    Visit: carergateway.gov.au
  - Family Advocacy
    Call: (02) 9869 0866
    Visit: family-advocacy.com
  - Side by Side Advocacy
    Call: (02) 9808 5500
    Visit: sidebyside.org.au
  - Young Carers NSW
    Visit: youngcarersnsw.org.au
• Community support organisations
  - IDEAS (Information on Disability Education and Awareness Services)
    Call: 1800 029 904
    Visit: ideas.org.au

Please visit our two websites for transition tips and resources:
• Trapeze
  Visit: trapeze.org.au
• Agency for Clinical Innovation (ACI)
  Transition Care Network
• HSNet is a website that lists services for ageing, disability, community, welfare and justice. Visit: hsnet.nsw.gov.au

• The Council for Intellectual Disability Visit: nsw.cid.org.au

• Ability Links Visit: abilitylinksnsw.org.au

• Intellectual Disability Rights Service Visit: idrs.org.au

• Adolescent transition clinics in children’s or adult hospitals
  - Trapeze
    Call: (02) 9382 5457
    Visit: trapeze.org.au
  - ACI Transition Care Coordinators
    Visit: aci.health.nsw.gov.au
    - Northern NSW area
      Call: (02) 4925 7866
    - Western NSW area
      Call: (02) 9845 7787
    - South Eastern NSW area
      (including Sydney Metro)
      Call: (02) 9382 5455

• National Disability Insurance Scheme (NDIS)
  Call: 1800 800 110
  Visit: ndis.gov.au

Taking care of yourself

Caring for a young person with an intellectual or developmental disability is a full-time job and sometimes it is easy to put your own needs aside. This can have an impact on your wellbeing and may even affect your ability to care and support your young person in the way you would like.

Some tips include:
• Eat healthily and regularly
• Exercise
• Sleep
• Negotiate sharing roles at home

• Talk to others about your situation
• Set aside time to spend with individual members of your family
• Ask for help when you need it, e.g. from family, friends or your GP
• Accept support from others
• Take time out for yourself to relax
• Do some activities, not necessarily related to your role as carer
• Work in a paid job
• Know your hospital resources, community resources and support groups

The importance of a (GP) for your young person

• It is important to have a good GP close to home.
• Check whether your GP is able to conduct a home visit if needed.
• Your GP should be your first point of call if your young person is unwell.
• Your GP will become the central person in your young person’s health care and will usually be the coordinator and referrer to any specialists required.
• Your GP can perform an annual health check (health assessment for people with an intellectual disability) that helps identify and manage your young person’s health needs.
• It is often advisable to ask for a longer appointment to enable your GP sufficient time to examine and discuss.
• Ask your GP to write a Chronic Disease Management Plan as this helps to make treatment goals for the next 12 months and provides Medicare funding for allied health services. A Mental Health Plan can open funding for psychological services
• The National Home Doctor Service provides after Hours GP Home Visits Bulk Billed.
  Call: 137425 (13SICK)
  Visit: homedoctor.com.au
Before leaving paediatrics

• From around the age of 14, talk with your paediatric teams about transition.

• From around the age of 16, ask your paediatric team or specialists who they recommend your young person should see in the adult health care setting.

• Request a summary of care and referral to adult services.

• Request copies of any relevant reports and imaging on DVD to provide to the adult health team.

• The children’s hospitals provide medical and allied health (e.g. physiotherapy, occupational therapy) care that may not be available from adult hospitals. You can increase your young person’s care options by seeing health care professionals in their private practice. Talk about this with your team. Organisations like Medicare, private health insurance, NDIS and Lifetime Care and Support might be able to provide financial support.

• Think about any special medication or equipment that is organised through the children’s hospital that will require planning for its continued use.

• Talk with your paediatric team about how to manage emergency situations during the time between the last children’s health appointment and the first adult appointment. An Emergency Management Plan may be useful.

Trapeze and the ACI Transition Care Coordinators are available to assist you through the transition process.

Carer and patient experience

The care provided in an adult hospital may be different to what was provided in paediatric care. For example, staying overnight with your young person at the adult hospital may have to be negotiated with the Nursing Unit Manager. This can be difficult for carers and young people, especially if your young person has complex behaviours and needs which respond to particular care or treatments. Contact the designated Carer Representative or Patient Friend at your adult hospital so they advocate with you and negotiate your young person’s needs. Remember that your young person has a right to appropriate health care. There are resources developed to support the communication with health professionals of what is relevant and appropriate for your young person to help in their care.

• Top 5
  Visit: bit.ly/2hmlJUL

• Admission2Discharge together
  Visit: a2d.healthcare

Medication

Most medications used in Australia are subsidised through the Pharmaceutical Benefits Scheme (PBS), where you will need to have a Medicare card. A Health Care Card can further lower the cost of medication for your young person. Once your medication costs in a calendar year pass a certain threshold, you and your family may be eligible for the PBS safety net. Visit: bit.ly/2wo4Fk4 for more information.

For medications that are not subsidised, you will need to pay privately or you can look into whether they can be covered through other special schemes.

If you obtain special medication through the children’s hospital pharmacy, check whether the adult hospital can continue to provide them. If in doubt, speak to the Head of Pharmacy at the children’s hospital.
Equipment/resources

If your young person uses equipment such as a wheelchair, standing frame, walking frame, shower chair, suction machine, air mattress, pump, humidifier, oxygen tank etc., check who the equipment belongs to. Sometimes the equipment may be on loan and will have to be returned when the young person transitions to the adult care setting. If your young person uses other resources such as feeding tubes, connections, special feeds, or formula, you will need to find out who supplies the resources and whether they will continue to supply them, or if a new referral and prescription will be required.

If you require equipment or resources, the specialist will help you apply for it or direct you to the appropriate people to help you.

Enable NSW provides equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication and self-care. Enable NSW is a Registered Provider to the NDIS.

Call: 1800 362 253
Visit: enable.health.nsw.gov.au

Legal matters

An enduring guardian is someone who can be appointed to make lifestyle, health and medical decisions for your young person when he/she is not capable of doing this independently. Decisions can also be made about where your young person lives, what services are provided to his/her home and what medical and dental treatment he/she receives.

• Law Access is a good starting point for finding out information about the law and legal issues. They can provide legal advice over the phone and link into relevant services.
  Call: 1300 888 529
  Visit: lawaccess.nsw.gov.au

• The Council for Intellectual Disability works with and for all people with intellectual disability to advocate for their rights and make life better in all aspects where possible.
  Call: 1800 424 065
  Visit: nswcid.org.au

• Planning Ahead Tools is a NSW government website with information about organising a will, power of attorney, enduring guardianship or advance care planning.
  Visit: planningaheadtools.com.au

Other legal resources include:

• NSW Trustee and Guardian
  Call: 1300 364 103
  Visit: tag.nsw.gov.au

• NSW Public Guardian
  Visit: publicguardian.justice.nsw.gov.au

• Legal Aid NSW
  Visit: legalaid.nsw.gov.au

• Aboriginal Legal Services NSW
  Visit: alsnswact.org.au

• Intellectual Disability Rights
  Visit: idrs.org.au
Financial matters

Many people with a disability can be supported to manage their own money. A family member can become a joint signatory on a bank account. Other avenues include becoming a payment nominee for their Centrelink entitlement, appointment of Power of Attorney or having one appointed from the NSW Trustee and Guardianship to look after their financial affairs.

If your young person is earning an income, including payments from Centrelink, they may be required to complete an annual tax return. In the case of an appointed guardian, this person would need to be the registered contact with the Australian Taxation Office. Often parents take on this role. People with disability may be eligible for tax and superannuation concessions and exemptions. For further information, contact the Australian Tax Office. Call: 13 28 65. Visit: ato.gov.au/individuals/people-with-disability

Australian Taxation Office

If your young person secures employment or receives other forms of income (including Centrelink payments), he/she will need to open a bank account and apply for a Tax File Number (TFN). The diagram on page 7 explains the process of applying for a Tax File Number.

Proof of eligibility

If you are applying on behalf of the TFN recipient, you must provide a current document that proves your authority to act on their behalf (proof of eligibility document). The proof of eligibility document should include both the TFN recipient’s name as well as your name. Acceptable proof of eligibility documents are:

- Australian birth certificate
- Medicare card
- Foreign birth certificate
- Letter of Attorney
- Power of Attorney
- Proof of parentage/guardianship documents

Department of Human Services (Centrelink)

Centrelink offers a range of payments including the Health Care Card to subsidise medication under the PBS.

Payment Finder can help determine what your young person is eligible for.

Call: 132 717 (Disabilities and Carers Line)  
Call: 132 490 (Youth and Students Line)  
Call: 131 202 (Multilingual support)  
Visit: bit.ly/2wnVrEv

MyGov

MyGov is a website that provides access to a range of online services in one place. Some of the These services include:

- Medicare
- Child Support Australia
- Australian Tax Office
- Centrelink
- Australian JobSearch
- MyHealth Record
- National Disability Insurance Scheme

Call: 132 307  
Visit: my.gov.au
Enrolling to vote

It is compulsory in Australia for all Australian citizens over 18 years old to enrol and vote in elections (federal, state and local). If your young person cannot understand the voting process, there are two options:

1. Temporary option. From 16 years old, you can notify the Australian Electoral Commission by telephone and ask for your young person to be placed on their exemption list which will last for five years before needing renewal.

2. Permanent option. From 18 years old, you can enrol your young person with the Australian Electoral Commission. Once enrolled, there is an “Objection claim that an elector should not be enrolled” form that requires a medical practitioner’s verification and if successful, this permanently removes your young person from the electoral roll.

Call: 132 326
Visit: bit.ly/2vvskT5

Post-school options

Leaving school is a significant transition point in the life of a young person with a disability. Your child’s school will normally provide you with lots of information and will support you through the post-school option application process. There are a number of useful resources available for you to help navigate this process and attending post-school options is a great way to get the latest information and learn about what services are available.

- National Disability Coordination Officer Program

- TAFE NSW
  Visit: tafensw.edu.au

- Universities: Each university will have their own Disability Support Service

- National Disability Insurance Scheme (NDIS) have School Leaver Employment Supports
  Call: 1800 800 110
  Visit: ndis.gov.au/people-disability/sles

- Disabled Australian Apprentice Wage Support Program. This is a government payment that assists employers of eligible Australian apprentices who have disabilities. For young people, this provides support with tutorial, interpreter and mentor services.
  Call: 132 717
Applying for a Tax File Number (TFN) and becoming your child’s registered contact for taxation purposes

Get some documents together

**Doctor’s letter**
Ask your child’s doctor to write a letter stating your child does not have the capacity to manage their own tax affairs

**Your letter**
Write a letter to the ATO requesting that you be your child’s registered contact

**Identification**
Gather some identification for:
- Yourself
- Your child
- Your relationship (to your child)

Apply for a Tax File Number

**Access TFN form through Centrelink**
A TFN application form can be provided at your local Centrelink office (on behalf of your child) while applying for a new Centrelink payment for your child.

**Apply through the ATO**
Fill out a TFN Application Form on behalf of your child. (You can get this form from any ATO Office or off the ATO’s website.)

Tax File Number received

Visit your local Australian Taxation Office with:
- Doctor’s letter
- Your letter
- Identification
- Your child’s TFN
Make sure you explain to the Taxation Office that you want to be registered as your child’s “registered contact.”

Visit your local Australian Taxation Office with:
- The completed TFN Application Form
- Doctor’s letter
- Your letter
- Identification
Make sure you explain to the Taxation Office that you want to be registered as your child’s “registered contact.”

You should now have the authority to take care of all your child’s taxation needs, including signing taxation forms on their behalf.